

## New NSDA Board Member Profile:

# SUSAN BECK

We are pleased to welcome Susan Beck to the NSDA Board of Directors! Susan is a lifelong Tennessee resident and currently lives in Louisville, TN. She is a graduate of Tennessee Tech University and the University of Tennessee with degrees in Computer Science and Industrial Engineering. Susan spent a large part of her early career providing seminars and workshops to customers worldwide in high-performance computing. She later consulted in a variety of areas including homeland security, telecommunications, and cable broadcasting. Susan currently works for a medical device manufacturer that is developing proton therapy equipment for cancer treatment where she leads a systems analysis/engineering team responsible for the company's software applications.



Susan developed adductor SD in 2016 and began getting Botox® injections at the Vanderbilt Voice Center in the fall of 2016. At the same time, she realized how important it is to have someone to talk to about SD so she volunteered to start a local support group for the NSDA. She now is the Leader of the Greater Knoxville Area Spasmodic Dysphonia Support Group. In addition, Susan jumped right in and has attended the last two NSDA Annual Symposiums, Leadership Workshops, and Dystonia Advocacy Day events in Washington, DC. In the Q & A below, she shares her diagnosis story and why volunteering with the NSDA is so important to her.

### **Share your SD journey with us. How did symptoms begin? What treatments have you used?**

I first started noticing strange symptoms in early 2016 at the age of fifty-six. I remember making a comment to one of my friends that my “teaching voice” didn’t seem to work anymore! I spent a large portion of my early career as a software instructor and definitely had developed my presentation or teaching voice during this time (ex: where I could speak to groups of ten or one-hundred and be able to project my voice accordingly.) By the spring of 2016 I noticed that I was experiencing breaks in my voice when I would try to lead a meeting of four or five people. It was very disconcerting to me because I felt like my voice sounded like I was nervous – and I knew I wasn’t nervous! I had done this hundreds of times before, so I actually found it to be quite embarrassing that I couldn’t make my voice work. Over the next few months, the struggle with my voice continued.

I tried to self-diagnose and experimented with every type of allergy medicine available, but nothing was working. I never really considered that I needed to seek medical help until a friend at work mentioned they had known someone that had trouble speaking and it turned out they had a polyp on their vocal cords. I made an appointment in June of 2016 with Dr. Christopher Rathfoot, an ENT in Knoxville. He diagnosed me with spasmodic dysphonia and a vocal fold nodule. On a return appointment a few weeks later, the nodule had healed with a treatment of steroids but the SD had gotten worse. Dr. Rathfoot wanted me to have a diagnosis confirmation from a Speech-Language Pathologist. Katherine Montouri, MS, CCC-SLP at UT Medical Center confirmed the diagnosis. I then worked with Dr. Rathfoot to schedule my first botulinum toxin injection appointment with Dr. Garrett at the Vanderbilt Voice Center in Nashville, which I received in late September of 2016. The botulinum toxin injections are working for me and I return to Vanderbilt every eight to ten weeks for treatment.

**How did SD impact your life, family, and career?**

When I first heard the words, “there is no known cause, and no known cure,” I truly couldn’t believe it. This diagnosis was so much worse for me than when I was diagnosed with cervical cancer ten years earlier. The cancer was caught early enough that surgery was the solution and I haven’t had any other problems since then. To hear that there is no cure for SD and that this is for the rest of my life, well, that was extremely difficult for me to accept. My family, friends, and co-workers were all very supportive, but I still found myself wanting to retreat from contact because it was just so frustrating to communicate.

**How did you get involved with the NSDA? What inspired you to start the Support Group?**

After my diagnosis, I started searching online for everything that I could find about SD. I found the NSDA website and it was so helpful to me. I am certain I read every single page of the website to gain as much knowledge as I could about this mysterious disorder. I also read the Bulletin Board and ordered materials. I read the book, *Speechless: Living with Spasmodic Dysphonia*, written by Dot Sowerby and *Easier Done than Said...Living with a Broken Voice*, by Karen Feeley. Reading about other people’s experiences with SD really helped me to understand the difficulties of SD and what I was facing.

During this time, though, I had not met anyone else that I could talk to that had this same disorder until I found out through my women’s Bible study group that there was another lady at our church that had SD! I arranged to meet her at church the next Sunday and was so grateful just to hear her story and how she has dealt with SD for over twenty years. Although our meeting was short, it was a turning point for me to get to the “acceptance” phase of having SD. I credit her with being my inspiration to start a local support group for SD. I’ve always been a very independent person and never understood the need for support groups until I learned first-hand how important it is to have someone to talk to about SD. I wanted to start a support group so that others that are faced with a SD diagnosis can have the same conversations and know that they are not alone in this journey.

**How has volunteering with the NSDA impacted you? What was a memorable experience?**

Since I became involved in the NSDA I have participated in the Dystonia Advocacy Day in Washington, DC in 2017 and 2018. Learning that SD is just one type of dystonia that affects our world has given me a new perspective on how important it is for all of us to work together to advocate for funding to advance research on all forms of dystonias.

I also attended the 2017 and 2018 NSDA Annual Symposiums and Leadership Training Workshops. Over my career, I have attended many types of conferences and symposiums. Nothing in my past prepared me for the feelings I would have for everyone that I met at the NSDA Annual Symposiums. I can only describe it as a “stress-free” family gathering where I know I have made friends for life in just the short time that we were together.

**What would you like to bring to the NSDA Board?**

I want to do everything that I can to support the NSDA mission to increase awareness of SD and other voice disorders, educate people on the need for fund-raising for research grants, and provide support to others that are struggling with SD.

**Anything else you would like to share?**

I’ve heard the horror stories of it taking ten years or more for someone to be diagnosed. I just can’t imagine going through that mystery for so long. The fact that I was diagnosed on my first visit to an ENT reinforces in my mind how much benefit the NSDA has provided to all of us. I am so grateful for all of the folks that have come before us to pave the way to finding the cause and cure for SD. Together let’s work to eradicate SD forever!